Measuring upper extremity muscle strength in children with Unilateral Spastic Cerebral Palsy

Valorisation Addendum

In this dissertation, valorisation is considered as "the process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use and (by making it suitable) for translation into competing products, services, processes and new activities" (definition taken from the report of the National Valorisation Committee, Waardevol: Indicatoren voor Valorisatie [Valuable: Indicators for valorisation] (2011) The Hague: Rathenau Institute, p. 8).

In this valorisation-addendum the following topics will be addressed:

1. social relevance of research results;
2. target groups to whom research results are of interest;
3. products/activities in which research results can be applied and formalized;
4. the extent to which research results can be called innovative;
5. how the valorisation plan will be implemented.

1. Social relevance of research results

Worldwide, CP is the most common motor disorder in childhood, with a prevalence in Europe of about 1.8–2.1 per 1,000 live births. Within the Dutch pediatric rehabilitation, CP is the largest group (>32%) receiving interdisciplinary pediatric rehabilitation treatments, resulting in high healthcare costs. Healthcare costs in Dutch pediatric rehabilitation in 2018 amounted to approximately 146 million euros.

Approximately 30% of all children with CP are diagnosed with unilateral spastic cerebral palsy (USCP). Muscle weakness of the affected upper extremity (UE) is one of the main characteristics of a child with USCP. Measuring muscle strength is a common activity in daily practice for most clinicians working with children with USCP in order to determine whether muscle strength weakness is present (discriminative) or whether muscle strength training has been effective (evaluative). In order to be able to measure changes in muscle strength, one needs to know the extent to which variations in measurement results occur between repeated measurements. This so-called measurement error may have several causes: the measurement instrument itself, the examiner(s) performing the measurement, the patient undergoing the measurement and the circumstances under which the measurement is performed.

This dissertation gives more insight into the (im)possibilities of measuring UE muscle strength in children with USCP in clinical practice.

Regarding the less-affected UE, only two studies had investigated muscle strength of the less-affected hand in children with USCP, with opposite conclusions. As it was not clear whether muscle weakness is a unilateral problem or whether both UEs have muscle weakness, we also researched the muscle strength of both UEs in children with USCP. This dissertation provides new insights into UE muscle strength in children with USCP (both affected and less-affected).

2. Target groups to whom research results are of interest

The results presented in this thesis are of interest to clinicians and researchers working with children with USCP. Our results can be used to 1) further optimize diagnostics and therapy (including the less-affected UE) and 2) to improve the use and interpretation of strength measurements for evaluative purposes.

Moreover, information about the Standard Error of the Measurement (SEM), Smallest Detectable Change (SDC), and the introduction of two new functional UE muscle strength measurement are valuable to the clinicians.

As the SDC values seem highly irrespective of the measurement instrument used or population studied, we advise that alternative ways to calculate the SDC should be considered. Therefore, the discussion of the dissertation is also interesting for statisticians and/or clinical epidemiologists who are interested in the smallest detectable change of measurement instruments.

To a lesser extent, policy makers can use our results to determine which interventions can be included during the development or update of clinical guidelines. Finally, this indirectly concerns health insurers because they can decide which (effective) muscle strength training intervention is reimbursed. and which is not.

3. Products/activities in which research results will be applied and formalised

Our measurement protocol is freely available and a large part of the measurement protocol has already been published as an appendix of the paper presented in chapter 4. If needed, we can train therapists in the (right) use and interpretation of measurement instruments.

We have also disseminated our results by presentations and mini symposiums at national and international conferences. After finishing this PhD, the dissemination of the results at national and international conferences will continue and a one-day symposium will be organised by Revant, Rehabilitation Centre Breda and Adelante Kenniscentrum in Hoensbroek, in collaboration with the Department of Rehabilitation Medicine (Care and Public Health Research Institute (CAPHRI)) of Maastricht University. The symposium is intended for clinicians and researchers.

As far as the cup and box tasks are concerned, we have chosen to use commonly available objects, so that they can easily be used by every clinician.

Recently, a computerised version of the cup and box tasks has been developed (activity Daily Life test and training Device-ADL-TTD), which can be used in research but also for training UE muscle strength. The ADL-TTD is also the first measuring instrument in which muscle strength during multiple (long lasting) dynamic functional tasks can be measured by a computer. Clinimetric properties of the

ADL-TTD are currently being researched. If the product is usable in clinical practice and clinimetric properties are acceptable, the product will become commercially available (under the license of Umaco b.v./ Procare b.v.)

4. The extent to which research results can be called innovative

Our study was the first study in which clinimetric properties of UE measurement instruments for children with USCP were researched in a study of good methodological quality as suggested by the COSMIN.

Although a few functional UE muscle strength measurement instruments are available, the Cup and Box tasks are the first functional muscle strength measurements in which the ability to maintain the strength in a sustained contraction can be measured.

Another innovation is that we showed that in children with USCP, muscle weakness is present in both UEs. As a result, measurement of both hands separately must be done in the diagnostic phase, and a bimanual strength measurement must be added. Besides, in case of muscle weakness of the less-affected UE, bimanual activity training seems to be more valuable than just providing unimanual training of the affected UE.

To our knowledge, we are the first research group to criticise the calculation of the smallest detectable change in upper extremity muscle strength measurements in children with USCP. Alternative methods should be considered.

5. How the valorisation plan will be implemented

As our research did not contain any intervention or product development, less can be said about the implementation of the valorisation plan. Information on how the knowledge/results are disseminated has already been mentioned in paragraph 3 of this addendum. Additionally, within our research network, the results have been disseminated with the message that:

- the measurement instruments studied are useful for clinical practice,
- measure the muscle strength in both arms
- measure different constructs of muscle strength, such as peak and endurance strength and certainly functional strength
- have the measurements performed by trained therapists
- measure multiple times, as described in our standardized measurement protocol, and
- use the measurement instruments we have researched.

What we can and will implement, is the use of the measurement instruments in regular rehabilitation and in highly intensive existing UE therapy camps for children with USCP. The findings regarding the muscle weakness of the less-affected UE will be communicated to the project leaders of the UE training camps and we will discuss with them what possibilities there are to pay more attention to the less affected UE. The "Handen in elkaar" platform and the CP-Net organisation will be invited to spread the knowledge in the Netherlands.

Regarding the calculation of the SDC, presented in chapter 6, we made an appeal that future research should focus on alternative ways to calculate the SDC. In the near future we will contact the members of the COSMIN team to discuss our results and recommendations regarding this topic to facilitate this research.